Kidney MAGAZINE

WINTER 2025

VOLUME NO. 3.1 | Winter 2025

10 MYTHS ABOUT WINTER ILLNESS

What you really need to know

NAVIGATING TOUGH TIMES

Through personal interests and traditions

MASTER THE ART OF BATCH COOKING

Eating well when short on time and creativity

PATIENT PARTNERS ADVANCING RESEARCH

Patient input is ensuring studies today have greater impact

THE BOND OF BROTHERS

The inspiring story of Kevin and Craig Settee

kidney
FOUNDATION

contents

Kidney
MAGAZINE

THE WINTER ISSUE

Winter 2025 | Issue 3.1

Publisher
The Kidney Foundation of Canada
BC & Yukon Branch

Executive Director
Pia Schindler

Senior Director
Communications and Marketing
Deborah Tucker

Managing Editor
Andrea Rudy

Art Direction
Andrea Rudy

Contact
200 - 4940 Canada Way
Burnaby, BC V5G 4K6
604-736-9775 or 1-800-567-8112
info.bcy@kidney.ca

Subscriptions
Andrea Rudy, Digital Communications
andrea.rudy@kidney.ca

letter from the editor

Dear Readers,

As the winter season unfolds and holidays have passed, we find ourselves in a time of quiet reflection. It is during these months that we have the opportunity to nurture our bodies and minds in meaningful ways. In this special winter issue of Kidney Magazine, we explore the unique challenges of living with kidney disease and ways to experience joy while staying well during the colder months. From batch cooking to provide healthy meals when our energy is low to embracing interests and traditions to improve our mental wellbeing, our goal is to inspire you to embrace the season with vitality and grace. Winter may bring its share of frosty mornings, but it also offers us the gift of renewal—a chance to reset and prepare for the year ahead.

One of the themes we're particularly excited about this season is the importance of self-care during the season of cold months and short days. Whether it's creating a morning ritual to start your day with intention or finding time to unwind with a good book and a cup of golden milk, winter encourages us to prioritize our health. In this issue, you'll find expert advice on managing stress, tips for staying safe in bad weather, and also read a powerful story about the bond of brothers.

Of course, staying active and nourished is key to thriving in any season. We've curated a collection of winter recipes that are as delicious as they are nutritious, and because health isn't just about the physical, we've included features on mental wellness, fostering meaningful connections, and finding joy in the little things. The Kidney Foundation's Kidney Wellness Hub offers many resources to support health and wellbeing year round.

As we look to the months ahead, let this winter be a time to honour your health journey, wherever you may be on it. Remember, wellness is not a destination but a lifelong practice, shaped by the choices we make each day. Our hope is that this issue serves as a companion and a source of encouragement, guiding you toward a season of balance and wellbeing. Wishing you warmth, health, and happiness this winter.

With gratitude,

Andrea Rudy

GOLDEN Milk

1 cup low-fat milk (can substiute low-fat almond milk)
1 tsp turmeric powder* (or freshly grated turmeric root if available)
½ tsp ground black pepper (helps with the absorption of turmeric)
½ tsp ground cinnamon (optional for added flavour)
1 tsp honey or maple syrup (adjust to taste)
½ tsp grated fresh ginger or ¼ tps ginger powder (optional)

In a small saucepan, heat the milk over medium heat until it’s warm but not boiling. Whisk in the turmeric powder, black pepper, cinnamon (if using), and ginger (if using). Continue to whisk until the spices are well incorporated and the milk starts to lightly steam. Reduce the heat and let the milk simmer for about 5 minutes. This allows the spices to infuse the milk. Remove from heat and stir in the honey or maple syrup to taste. If you used fresh turmeric or ginger and prefer a smoother texture, you can strain the milk through a fine mesh sieve or cheesecloth.

Perfect for a soothing bedtime drink or a morning pick-me-up. Feel free to adjust the spice levels and sweetness according to your preference.

*Excessive turmeric or spices can put a strain on kidneys, so be sure to consult with your healthcare provider when incorporating new foods into your diet.

With its lower sugar content, golden milk is a great alternative to hot chocolate for a warm treat on those colder days.

10 myths about winter illnesses

Health myths are ever-present and thrive on half-truths—a mix of outdated beliefs, misinformation, and anecdotal experiences passed down without scientific scrutiny.

Contributor: Dr Micheli Bevilacqua, MD, FRCPC, MHA, CHE

These myths often arise because of old misconceptions or misunderstandings about the body and illness. There are several common myths about winter illnesses that persist, despite not being entirely accurate. Here are some of the most widespread.

1

COLD WEATHER CAUSES COLDS AND FLU

The flu and the common cold are caused by viruses. While people tend to get sick more often in winter, it's because they spend more time indoors in close proximity to others, which increases the chance of spreading germs, not because of the cold weather itself.

2

GOING OUTSIDE WITH WET HAIR CAUSES ILLNESS

Illness is caused by viruses and bacteria, not wet hair. While cold temperatures can weaken your immune system slightly, they don't directly make you sick. Wet hair might make you feel colder, but it doesn't lead to illness.

3

YOU CAN'T GET SICK FROM THE FLU SHOT

The flu shot contains inactivated viruses (or in some cases, parts of the virus), which cannot cause infection. Some people may feel mild side effects, like soreness or a low-grade fever, but this is not the flu itself.

4

BEING COLD WILL WEAKEN YOUR IMMUNE SYSTEM

While long exposure to extreme cold can stress the body, moderate cold temperatures do not significantly impact the immune system. It's more about how close people are to each other indoors during winter months.

5

YOU ONLY GET SUNBURNED IN SUMMER

Even in winter, the sun's UV rays can damage your skin, especially if you're outside in the snow or at high altitudes, as snow reflects UV rays. Wearing sunscreen is still important during winter months.

6

THE FLU IS JUST A BAD COLD

The flu is generally more severe than a cold. It often comes on suddenly, causing fever, body aches, fatigue, and more serious complications like pneumonia in some cases, particularly in vulnerable populations like the elderly or those with chronic health conditions.

7

NATURAL COLD REMEDIES ARE ALL SAFE

Just because something is listed as 'natural' or available to buy without a prescription does not mean it is safe for everyone. Some over-the-counter medications or supplements that are safe for others can be dangerous in people living with kidney disease. Check with your kidney team before taking any over-the-counter medication or supplement.

8

THERE'S NO WORRY ABOUT DEHYDRATION IN WINTER

Dehydration can occur in winter,

too, especially because people often drink less water due to lower thirst cues in cold weather. Dry indoor heating also contributes to water loss. It’s important to stay hydrated year-round.

9

STARVE A FEVER, FEED A COLD

The body needs nutrition and hydration to fight off any illness. Whether you have a cold or fever, eating a balanced diet and drinking fluids are essential to help your immune system function properly.

10

VITAMIN D DEFICIENCY DOESN’T HAPPEN IN WINTER

Vitamin D deficiency is common in winter, especially in places with less sunlight. The body makes vitamin D when exposed to sunlight, so it’s a good idea to consider vitamin D-rich foods or supplements in winter.

master the art of *batch cooking*

Adapt base recipes and freeze double batches for days short on creativity and time.

Contributor: Dani Renouf, RD, MSc

When preparing meals in bulk, not only do you save time and money, you can ensure healthier choices. Controlling ingredients helps reduce the need for processed foods and allows the incorporation of fresher, nutrient-dense options like vegetables, whole grains, and lean proteins, which are vital for kidney health.

Batch cooking is an excellent strategy for both health and budget management.

Many of us struggle these days to balance healthy cooking with rising grocery prices, and combined with hectic schedules, meal prep becomes all the more difficult. For kidney-friendly diets, the challenges can seem ten-fold. Living with chronic kidney disease (CKD) or other kidney-related conditions can require careful dietary management. Often we end up making the same meals for simplicity and lose out on a variety of foods.

Batch cooking can be a valuable tool in maintaining a kidney-friendly diet while saving time and ensuring nutritional balance, including controlling sodium, potassium, and phosphorus levels.

Reduce decision fatigue by having pre-prepared meals and remove the stress of deciding what to cook each day, ensuring adherence to dietary recommendations.

When preparing meals in bulk, you can ensure healthier choices by controlling ingredients, reducing the need for processed foods and incorporating fresher, nutrient-dense options like vegetables, whole grains, and lean proteins. From a budget perspective, buying ingredients in larger quantities often saves money, and meals prepared ahead of time reduces the temptation to eat out or order takeout, which can be an additional expense.

Chicken Chili

Most chili recipes are loaded with salt and high potassium beans, but this is a wonderfully fresh-flavoured chili stew that needs no salt. This double batch makes 8 dinner servings or 16 lunch-sized servings.

Makes 8 2-cup servings

- 2 lb chicken breasts, cut into bite-sized pieces
- 5 cups cold chicken broth (use a "No Salt Added" brand)
- 8 cloves garlic, finely chopped
- 2 jalapeno chilies, seeded and diced
- 2 tbsp flour
- 2 red peppers, diced
- 2 carrots, diced
- 2 cups frozen corn
- ½ tsp freshly ground pepper
- 1 tsp ground cumin
- 4 tbsp cilantro, finely chopped
- 2 tbsp cornstarch
- Unsalted or low-salt tortilla chips (optional)

In a large saucepan, heat 1/4 cup broth to boiling. Cook chicken in broth, stirring, until white (about 4-5 minutes). Remove chicken and set aside. Cook garlic and jalapenos in broth over med-high heat stirring frequently (about 2 minutes). Stir in flour, turn heat to low and stir constantly for 2 minutes. Gradually add 2 cups of broth. Add chicken, red pepper, carrots, corn, pepper, cumin and cilantro and heat to boiling. Reduce heat, cover and simmer approximately 20 minutes until the chicken is cooked all the way through. Mix cornstarch in remaining 1/4 cup of broth and stir into stew. Continue to cook, stirring often, until heated through and thickened. Serve topped with crushed tortilla chips and extra cilantro.

Base Recipe Option

Double up the broth and leave out the cornstarch for a warm and satisfying soup, or use as a filling in stuffed peppers or lasagne.

(from the Kidney Community Kitchen)

A key component of batch cooking is using base recipes that can be adapted into different meals to provide variety throughout the week.

Our Chili Chicken, Black Bean Burgers, and Cabbage Steak recipes have been doubled to freeze and use in alternative dishes for easy variety in weeknight meals to reduce food waste and make meal prep more efficient. Dividing meals into appropriate sizes before freezing helps ensure portion control and adherence to your dietary plan.

Pro Tips for Successful Batch Cooking

Plan Ahead: Create a weekly or bi-weekly meal plan based on your dietary needs and preferences.

Cook in Stages: Prepare grains, proteins, and vegetables separately to mix and match for variety.

Taste Test: Adjust seasonings and ingredients to ensure meals are flavourful despite lower salt levels.

Keep a Log: Track meals and ingredients to ensure compliance with your kidney-friendly diet.

The Kidney Wellness Hub and Kidney Community Kitchen offer two meal planning tools to help you create customized meals tailored to your dietary needs, making the process convenient and efficient. Visit kidneywellnesshub.ca.

Roasted Cabbage Steaks

Freezing cabbage steaks helps preserve their nutrients, extend shelf life, and makes them a convenient option for quick, healthy meals.

1 large green cabbage	2-3 tbsp olive oil
Pepper to taste	Garlic powder (optional)
Paprika (optional)	

Preheat your oven to 400°F (200°C). Remove any tough or damaged outer leaves from the cabbage. Slice the cabbage into 1-inch-thick steaks. Place the cabbage slices on a baking sheet lined with parchment paper. Brush both sides of each steak with olive oil. Sprinkle with pepper and any other seasonings like garlic powder or paprika for added flavour. Roast in the preheated oven for 20-25 minutes, flipping the cabbage steaks halfway through until golden brown with slightly crispy edges. Allow the cabbage steaks to cool completely to room temperature. Once cooled, place the cabbage steaks on a baking sheet in a single layer, making sure they're not overlapping. Freeze 1-2 hours or until the steaks are frozen solid. Transfer the frozen cabbage steaks into an airtight freezer-safe bag or container. Store them in the freezer for up to 2-3 months. (6-7 servings)

Reheating Frozen Cabbage Steaks

Preheat the oven to 400°F (200°C). Place frozen cabbage steaks directly on a baking sheet. Roast for 15-20 minutes until heated through and crispy on the edges. Cabbage steaks are easy to customize. Top with crumbled feta, toasted panko, grated parmasean, your favourite herbs, or drizzle with tahini dressing.

Base Recipe Options

Chop cabbage steaks and mix into a vegetable soup for a more filling meal with deeper flavours. Add to lentils and brown rice and top with a garlic yogurt or tahini dressing for a warm salad.

the underrated veggie meatball

Veggie meatballs are a versatile and nutritious option that can be used in a variety of dishes to suit different tastes and cuisines. They can be served with classic pasta and marinara sauce for a plant-based twist on spaghetti and meatballs, or used in a sub sandwich with lettuce and hummus for a satisfying meal. In soups, veggie meatballs add a hearty texture and flavour, and you can also use them as a protein boost in grain bowls, salads, or wraps, pairing well with fresh veggies, lentils, and dressings. Their adaptability makes them a great option for quick and creative meals.

Prepped in bulk, meatballs made from this black bean burger recipe (opposite page) cost pennies a piece, making them a fantastic, inexpensive way to save money and time while eating a nutritious meal.

Remember to choose alternative meal options based on your personal dietary requirements.

the versatile veggie burger

Make this double batch of flavour-packed black bean burgers and freeze half as meatballs. Toss in soups, pasta, salad, or on a sub sandwich for an easy but delicious midweek meal.

Black Bean Burgers

2 15 oz tins, low-sodium black beans
1 cup flax meal
2 tbsp smoked paprika
2 tbsp Worcestershire sauce
2 large eggs
4 tbsp onion powder
2 tbsp cumin

Preheat oven to 400 degrees F. In a large mixing bowl, smash the beans with a fork or potato masher. In a small separate bowl, whisk the egg and Worcestershire sauce. Add egg mixture to the beans and smash until well mixed. Add in the flax meal and spices and smash together until the mixture is well blended. Divide batch. Form half the dough into four equal-sized patties and place on a cookie sheet that is lightly greased or lined with parchment paper. Using a fork, pat down the patties so they resemble meat patties. Bake for 15-20 minutes on each side. Internal temperature should reach 165 degrees F; continue cooking until final temp is reached.

Base Recipe Options

Form remaining half into meatballs and freeze on a tray before transferring to a freezer bag. (See opposite page for creative ways to use veggie balls.)

Craig and Kevin Settee, Fisher River Cree Nation
Image from UHN Centre for Living Organ Donation “Great Actions Leave a Mark Campaign”

Bond of Brothers

The inspiring story of Kevin and Craig Settee: how family and community supported a journey from diagnosis to transplant

Contributor: Deborah Tucker

Kevin and Craig Settee were very young when they faced some extremely adult issues. At only ten years of age, Kevin and his family received the devasting news that he had kidney disease, a diagnosis which changed his childhood.

Surrounded by the love and support of his family and community including from his brother, Craig, who eventually donated one of his kidneys to Kevin. Kidney Magazine (KM) spoke to the brothers about their journey.

> **I always wanted to be like my big brother.**

KM: Thank you, Craig and Kevin for sharing your story with us. How did you first know something was not right with your health, Kevin?

Kevin: I was at my grandparents' place for a sleepover, and I remember being sick with a fever and chills. Just not feeling one hundred percent. When I woke up the next morning, I went to use the bathroom and my urine look really dark—it almost looked like blood. I got really scared. I called my dad and my grandparents and said, hey, look at this. Something's wrong with me, I think. Everyone got worried.

We went to the family doctor, and they did some tests and I got my first needle. I remember that was very scary for me, getting my first needle. I remember I was shaking; my arm was shaking. The results came back fairly quickly, and they said I'd need to go to the hospital. I think it was like the next day. I remember meeting with a pediatric nephrologist—a kidney doctor they told me—and they did more tests. By the end of the week, we learned I had kidney disease. I had more tests over the next month and then started different medications to try to put me into remission because my kidneys were suffering.

That whole experience was hard for me. It was also a confusing time and a scary time. And, in terms of symptoms, I didn't really feel much, just aside from when I was sick, but I did have to adjust to some of the medications. But, you know, I'm glad that we have a good healthcare system here in Canada and have really good doctors at the Health Science Centre here in Winnipeg. They helped me a lot.

KM: You were so young when you were diagnosed. How did life change after your diagnosis of kidney disease?

Kevin: I think our childhood was good, much like many other kids our age. For me, I felt like I was surrounded with a lot of love and opportunity. Growing up in Winnipeg, there was always lots going on. But I also really enjoyed getting out of the city. Our grandparents were a big part of our childhood, and they used to take us to our family cabin on Matheson Island in Manitoba every summer. And, of course, I had a big brother to look up to as well. I always wanted to be like my big brother.

Craig: I would share Kevin's sentiments. Lots of fond memories. We were a very close family. Growing up, we had our paternal grandparents who took us to Matheson Island, as Kevin said, and our grandparents from my mom's side of the family who instilled a lot of Indigenous teachings in us. While we didn't know it at the time, it would help guide us in the years to follow. They took us to a lot of places, including the reserve in Dauphin River First Nation in Manitoba where my mom lived until she was elementary school age and then she moved to Winnipeg with her mom. We grew up in the inner city of Winnipeg in a neighbourhood with lots of other kids our age, with summers filled with bike rides and in the winter it was all about hockey. We played on a little ice rink we built ourselves. We didn't have cellphones or access to the internet yet, but we did have a real sense of community.

Kevin: I got sick more frequently and I felt like the sicknesses were getting more intense. I was also getting really bad cramps all the time, including when I tried to play sports. I'd be sick during hockey games, but I would still play even though I was sick. Sometimes I'd have to get off the ice and sit in the dressing room. My dad or mom would come in and support me. Sometimes this all made me cry and I remember thinking, why am I going through this? I know I shouldn't be experiencing this at such a young age. I just want to play hockey. So that was really hard to go through.

KM: Aside from the physical symptoms, you also mentioned the isolation you felt. Can you explain what that was like?

Kevin: It was hard because I was young, and I didn't know anybody else my age who was going through what I was going through. I didn't really have people to really talk to. The only

time I had an opportunity to hang out with other kids who were affected by kidney disease was when I went to the Kidney Foundation's Camp Stevens in Ontario, and we all stayed in the cabin together and it was really fun. It felt good to be around other kids who were experiencing similar health issues. I think at that time I was in remission, so I was feeling pretty healthy. I felt a bit more normal. But it wasn't until dialysis that I really experienced isolation and really had to kind of pull myself up often.

KM: Tell us about your experience on dialysis.

Kevin: It all happened pretty quickly. The doctors told me my kidney function was going down fast when I was 18 or 19 and that I'd have to start thinking about dialysis, and if I wanted peritoneal or hemodialysis. It was crazy all the things coming at me. I was 19 when I started peritoneal dialysis and was on it for two years. I knew about dialysis because my grandfather had kidney disease and we used to go visit him when he did his dialysis in Winnipeg. I remember the fistula in his arm. That really stood out to me as a young kid. I also knew how hard kidney disease and dialysis was for him, and so when I was told I had to start dialysis, I had a lot of apprehension.

Dialysis meant some real changes in my life also, including not being able to play contact sports like hockey or travelling. I love adventure and meeting people and all that was a lot more challenging. That led to more feelings of isolation. So, yeah. That's a lot as a young person on anyone. Right? A lot on your shoulders to have all these things coming at you so quickly.

KM: Kidney disease does not just affect the patient, but the whole family. As Kevin's only sibling how did his diagnosis impact you, Craig?

Craig: I'm five and a half years older than Kevin, so when he was diagnosed I was in my teens and in high school and I didn't fully understand the extent of the diagnosis of chronic kidney disease. I guess I was just trying to navigate being a teen and not sure what this all meant. I knew Kevin was taking medications for his kidneys and our parents would go to appointments and look after him. What I did notice was the effects of some medications on Kevin, which caused him to retain a lot of water. I also knew how hard the cramps were for him and that he didn't have the energy levels and couldn't exercise like before. He's a really good athlete but his body wasn't allowing him to perform how he wanted it to or to spend the time that he wanted to playing sports like hockey, lacrosse or baseball or even just riding his bike around.

But I really didn't dive a lot into educating myself about kidney disease at that point. I think it took me a bit longer until my early twenties when the disease started to progress. We started to hear conversations with the health care team around potentially looking at options for going on the transplant waitlist and looking for a living donor. That's where I think it piqued my interest a lot more about what's going to happen next.

KM: Craig, you have said being Kevin's kidney donor was something you needed to do. Tell us about that.

Craig: When the conversations started to happen with Kevin and my parents about finding a living donor, I would attend some of the appointments as well. We talked about who do we reach out to in the community and how. Both my parents were facing some of their own health issues, but fortunately for us our mom is a really gifted planner and organizer and so she was really able to help put that call out, reach out to people from our Indigenous community and people from our ceremonial community. My mom's also an educator and so she shared that message with that community, too.

And, of course, we did a lot of prayers as well asking for the wellness of my brother. Part of these prayers I think, for me, was to be able to be that donor. A lot of people stepped up to be tested, including my uncle. I also wanted to be tested.

Through the many conversations we had, I began to discover something about myself. It was a deep knowing that I wanted to be Kevin's donor. I wanted to do this for him.

I wanted to go through the process and be tested. So that's exactly what I did.

Turned out Uncle and I were the closest matches for Kevin, but because of some of our uncle's health issues, I was the best match. I was very happy as I wanted to be that person and do that for my little brother. I remember how thorough the donor work up process was, which is good. They really make sure you are healthy in all ways. I remember the session with the psychologist and exploring why I was doing this. I said it's my family. I said that's my little brother. I'm doing this because I want to see him not be on dialysis and to be able to live that life with a new kidney. You learn a lot about yourself when you step up to be a donor, it's not just physical but mental and spiritual as well.

KM: Kevin you said as a child you always looked up to your big brother Craig, and wanted to be like him, so what was it like to learn he was now going to your kidney donor?

Kevin: I'll share a little story. My mom, Craig, and his fiancé were going for a meeting at the hospital; it was kind of like the last meeting with the transplant team to determine whether or not I was going to be the right match. I was sitting in the parking lot because I couldn't go. I remember sitting there, just waiting and waiting and waiting. It was very hard because I remember my uncle when he came to my place to tell me he wasn't the right match. You just never know. But as I sat there waiting, all these questions kept going through my mind. Am I going to have to do dialysis forever? Am I going to survive? There were some nights where I felt like I wasn't going to get through it all.

So, as I'm thinking about all this stuff, I get a phone call from Craig who said to come and meet them outside. I remember they were across the street and I was on the other side and we walked and kind of met halfway on the street.

What I could see made my heart almost stop as they all looked kind of sad. And then a second later I could see my brother kind of smile, and then they all started smiling. And then Craig gave me a hug and said, yeah, I'm going to be your donor.

And I just remember thinking, yes, yes, yes! Words cannot describe how happy I felt.

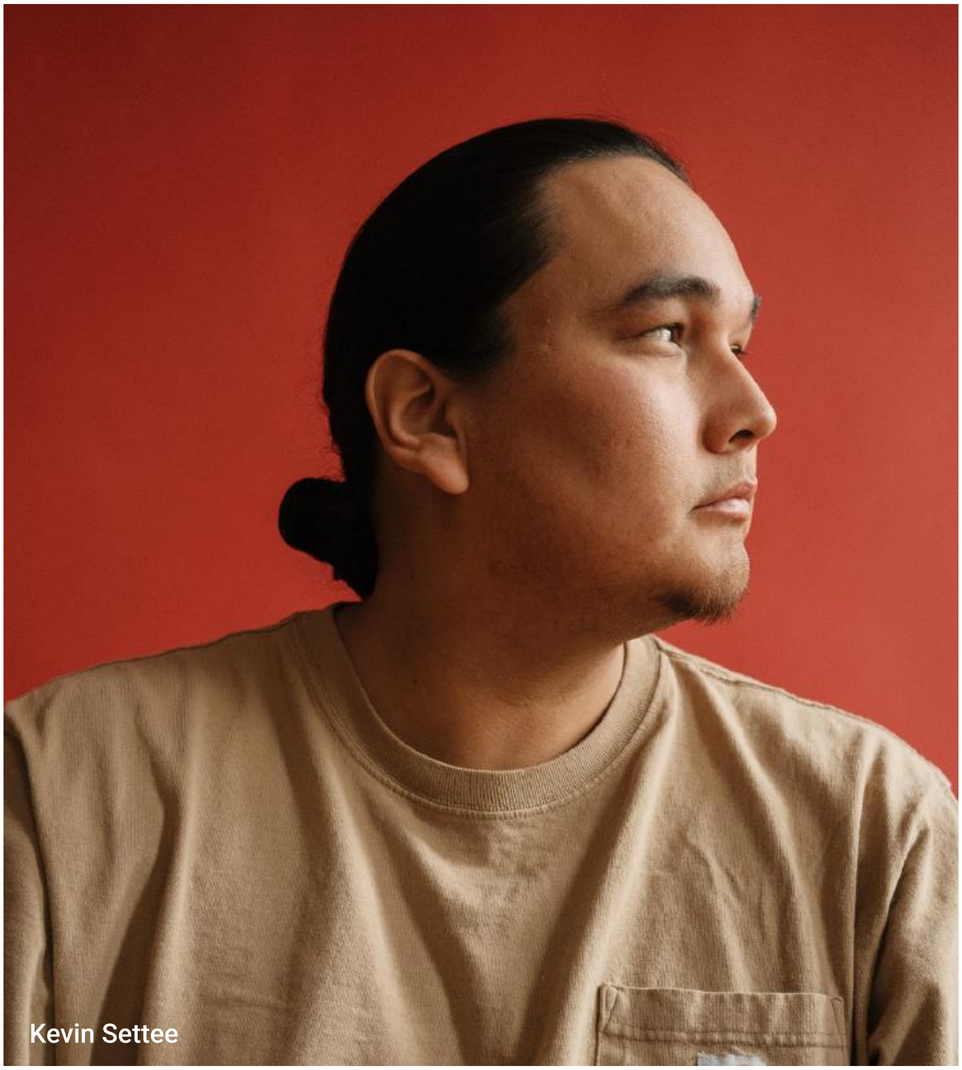
As Craig said to me after, in the darkest of times sometimes we need to find humour in some way. Even though the humour can seem dark as well, it can help. The laughter and joy it brought us after and sense of relief, it was good for all of us. I remember them saying they want to do the transplant right away. And even though my wait time for surgery was only a few months, it seemed like eternity.

KM: Yes, many people say the waiting is the hardest part throughout the process. But when the day of surgery finally did arrive, describe for us what that was like.

Craig: The healthcare team was excellent, explaining exactly what would happen. But it didn't feel real to me until I was being wheeled down the hallway on the morning of the transplant. So, it's like, all right, this is happening. Seeing my mom and my partner and hearing them say we'll see you on the other side. See you in the recovery room and, yeah, that's when it got real for me. And I just remember those questions in the operating room, you know, what's your name? What are we doing today? Kidney. Kidney transplant. Which kidney? Count to ten for me. And then I was out.

Kevin: You know getting worked up to receive this kidney is incredible, I mean, emotionally, physically, everything. I remember going into the hospital as I did my last dialysis at home that morning. I remember getting wheeled into the operating room and the surgeon had music playing on the radio. I guess he liked listening to music while he performed operations. I remember a nurse looking at me and saying it's going to be alright and to try to relax because my heart rate was beating so fast as I was pretty nervous. And then I too remember them asking me to count to ten. And in a millisecond I was asleep.

And when I woke up, the first thing I did was I put my hand on my stomach and my catheter was gone and so I knew that my kidney was working. I remember feeling overwhelmed with emotion. And my mom was there, and she said, Kevin, everything went great. And you're going to be okay. And the doctors came up to me and said the same thing and told me several times to just rest and not to move around too much. I remember putting my headphones on and listening to


Kevin Settee

music and falling back asleep and then waking up in the room with my brother.

KM: Kevin, tell us about waking up after surgery and seeing Craig in your room.

Kevin: It was pretty intense. Craig and I were always very, very close. I think this process just reinforced all that and brought us even closer. I just felt this incredible bond and really indebted to my brother. But, you know, the way that I have thought about it is like I've been given a second chance at life.

> *The best way to honour my brother is to live the best and most fulfilling life that I can and to take care of the kidney. To live healthy and eat well and not drink and take care of myself and take care of my kids.*

KM: And for you Craig, how did you feel?

Craig: I felt pretty good. But for me, I knew I'd be OK, I was just so happy my transplanted kidney was working and to have my little brother feeling better. That was the biggest gift for me. It was funny to see the celebrations when he was able to pee, because they know then that the kidneys were working. I'd never seen people laughing and giving high fives and cheering for one to go to the bathroom. Plus, I was very grateful that we got to be in the same room together after surgery to heal and recover together.

KM: Now that it's twelve years since the surgery, how are you both doing?

Kevin: I'm doing really well. I think we're both doing really well. Our lives are full with families and work. Even though we don't get to see each other as much as we want—I live in Winnipeg and Craig's in Vancouver—we have an incredible bond and connection.

Craig: As Kevin said, we are very close, and this definitely strengthened our bond. I am always going to look out for him and support him and be there for him. I think probably the greatest way that I could be there for him is to literally give him a part of myself and just recover and live life together. But I like to joke with him, too. We dress the same sometimes, like wearing the exact same outfit or same colour shoes, and not on purpose.

> *I joke about how my kidney is influencing his clothing choices.*

KM: You both speak about having a lot of support from your family and community.

Craig: Kevin and I are really appreciative of the incredible support from our own community. For example, when we were getting our work up done for the transplant, we held a fundraiser in Winnipeg. It was called a blood, sweat, and steak thing. We had food, music, silent auction, door prizes and people from our community bought tickets to come to the event and really supported us financially. That really helped us take the time we needed to recover from surgery, as well as with comfort items to make our recovery easier. We are also grateful to the Kidney Foundation and their Living Organ Donor Expense Reimbursement Program, which also supported us with out-of-pocket costs related to transplant expenses. We are so grateful for all our friends, family and our wider community who put us in their prayers and helped us with emotional support.

KM: This has been a life-changing experience for you both in so many ways. I understand you've made it your mission to share your story to help others in similar situations, and raise awareness about the importance of organ donation.

Kevin: I think for me, because of the health issues that I went through and because of my parents' health issues, I really had to learn how to handle life—how to deal with life when it gets hard and difficult. I felt like going through all this at such a young age really prepared me for the challenges of life and how to deal with hard situations and, so, yeah, during that time I learned life hacks, I guess to help me, help myself.

I really understand the importance of health and taking care of myself and encouraging other people to take care of themselves as well. Just like that term—your health is your wealth. And it's really true because I remember going home from the hospital and my body felt so light, like I felt like my body was like a feather. I felt like my vision was so clear, like I could see everything so clearly. And, yeah, when you're sick, sometimes you don't even notice that what you're going through is not normal. I really understood that when I got home.

I always try to remind people we need to take care of ourselves to the best of our abilities. I would just say for Indigenous peoples not to be scared of transplantation, not to be scared of receiving a kidney or giving a kidney as well. To help give someone a second chance at life. I think everybody deserves to live. And I don't think that people should feel bad for receiving a kidney, because I think some people do feel bad. I think some feel wary of it or they feel they don't deserve it, but I'm a firm believer we all have gifts, and we all have a purpose. And that if you need an extension of life, you should take it and live out your life to the best of your abilities.

Craig: We share our story wherever we can. We've been able to travel across the country and internationally, as well. That's really opened opportunities for us to also connect with the kidney community, connect with other people who are organ donors and organ transplant recipients and hear their stories, as well. We had an opportunity to travel to Australia to the World Congress of Nephrology Conference and share our experience and to also hear experiences from other Indigenous people from New Zealand and Australia.

We also participated in an organ donation campaign called Great Actions Leave a Mark. It's about being proud of the scars from being an organ donor and that those scars represent the gift of life. We also had the opportunity to partner with Dr. Caroline Tait, Canada Research Chair, University of Calgary, to produce an animated video, called "Sacred Gift," based on our story. Kevin is a photographer and also works in the film industry, which helps us share our story, and I work as a project and team coordinator with the First Nations Health Authority. But we also do a lot of volunteer work, including my role as a board member of the Kidney Foundation, BC and Yukon Branch.

One of the most positive things about sharing our story has been people asking us about kidney disease and the process of becoming a donor. We're so happy to have those conversations.

> ***Stories are a great way to impart information and if there's any way our experience or story can help make someone's kidney journey easier or help someone think about becoming an organ donor, then that's a big win in our books.***

We plan on doing this for a long time. Let's just say we have lots of story left in us to tell.

KM: Well, you have a very inspiring story to share. Thank you for sharing it with Kidney Magazine.

patient PARTNERS

Patient partners provide lived experience and unique insights that ensure studies are relevant, inclusive, and impactful for those they aim to benefit.

Contributor: Julie Wysocki, Acting Director, Research, Kidney Foundation

Patient involvement in research has emerged as a cornerstone of modern medical and scientific advancements.

Gone are the days when patients were seen as passive recipients of care; today, they are active collaborators, shaping the research agenda to better address real-world needs. This approach not only enriches the research process but also delivers tangible benefits to both patients and the broader healthcare community.

When patients contribute to research, they provide unique insights grounded in lived experience. Their perspective helps researchers by highlighting issues that matter most to their communities, ensuring research focuses on real-world problems.

There is also a direct, positive impact on those engaged in research. Patient partners can gain a deeper understanding of their conditions and the research process, ensuring they are better equipped to advocate for their health needs. Participating in research empowers patients by giving them a voice in shaping the future of healthcare. Sharing their experiences also encourages others to participate in research, amplifying the collective impact, while sustained collaboration leads to ongoing improvements in healthcare systems.

In 2011, the Canadian Institutes of Health Research (CIHR) launched the Strategy for Patient-Oriented Research (SPOR) with a vision to “demonstrably improve health outcomes and enhance patients’ health care experience through integration of evidence at all levels in the health care system.” Can-SOLVE CKD Network, one of the five chronic disease networks funded by SPOR, has become Canada’s largest-ever kidney research initiative. Can-SOLVE’s patient-led initiative, Kidney Check, focuses on developing early detection programs for CKD in at-risk communities. (The Kidney Foundation of Canada was one of several funding partners supporting Kidney Check.)

Dr. Adeera Levin, one of the Network’s co-principal investigators, shared how patient partner and community members worked together with the research team to define an approach that is patient- and community-centric. This approach has resulted in a program that is more relevant and meaningful to those it serves and has enhanced uptake of the screening program. “As a result, the team has been welcomed into communities, conducted many engagement sessions. and provided screening and kidney health education to more than 500 participants in British Columbia alone.”

Overcoming Barriers to Patient Participation

Despite its benefits, patient involvement in research faces challenges, including lack of awareness, logistical barriers, and misconceptions about the research process. To address these issues, stakeholders are working on raising awareness and educating patients about research opportunities and their potential impact.

The Kidney Foundation understands that encouraging patient participation is not just an ethical imperative but a strategic advantage that can propel healthcare innovation to new developments. To help studies in need of patient partners, the Foundation has dedicated a page on kidney.ca to share opportunities to participate in a study or clinical trial. The involvement of patients in research is more than a trend—it is a transformative approach that bridges the gap between science and society. By integrating the voices of those most affected by medical conditions, research becomes more relevant, impactful, and human-centered.

Canadian studies requiring patient input on experiences with CKD, diet quality, knowledge of precision medicine, IgA nephropathy and other knowledge areas are added to the list on an ongoing basis. There are also a number of clinical trials posted, as

ADVANCING RESEARCH

well as opportunities for those with lived experience in kidney disease wishing to become engaged in research to assist as a peer reviewer. In collaboration with the Canadian Donation and Transplantation Research Program, Can-SOLVE CKD, Canadian Nephrology Trials Network, The Kidney Research Scientist Core Education and National Training (KRESCENT), and a working group of lived experience reviewers, The Kidney Foundation of Canada developed a peer review module to provide training for those who want to participate in the peer review process.

The KRESCENT Program's main goals are to enhance kidney research capacity in Canada and to foster collaborative research and knowledge translation. It has also implemented a robust lived experience engagement process to further patient involvement in research. The Patient Community Advisory Network (PCAN) is embedded within the KRESCENT Program to provide valuable leadership and mentorship to KRESCENT trainees on how to engage patients in research. People with Lived Experience also take part in the peer review process for the KRESCENT Program. Patient engagement in research will continue to evolve and remain a central component in The Kidney Foundation of Canada's research programming.

Nancy Verdin shares how being a patient and family advisor with KRESCENT has given her two important opportunities. "First to work closely with new investigators to help them understand the role of patient and family advisors in all levels of research. Secondly, working closely with our diverse and growing patient and community network I have learned more about lived experience and the wealth of knowledge our members bring with them."

Today, patient-oriented research is playing a critical role in advancing kidney disease research and improving outcomes for patients living with chronic kidney disease, end-stage renal disease, and other kidney-related conditions. By incorporating patient feedback, researchers can create study protocols that are more practical and participant-friendly. Co-creation with patients can result in therapies that are more tailored and effective. When patients are involved in research, it strengthens the trust between them and the scientific community.

> **By integrating the voices of those most affected by medical conditions, research becomes more relevant, impactful, and human-centered.**

Tips for patient partners to maximize their contributions and experiences in research.

Understand Your Role

Understanding your role, responsibilities, and how your input will shape the research clarifies expectations.

Share Your Thoughts

Don’t hesitate to ask questions if something isn’t clear. Your lived experience is invaluable—be open and honest about it.

Build Relationships

As a patient partner you are an important member of a collaborative team. Represent your community’s voice and bring back learnings to them.

Set a Schedule

Maintain notes on meetings, decisions, and your contributions. Set boundaries in order to manage your time and energy, especially if you’re juggling personal health concerns.

Advocate for Inclusivity

Encourage the research team to use plain language and consider diverse perspectives. Advocate for the inclusion of underrepresented groups in research design and recruitment.

Take Care of Yourself

Know your limits. Engage at a level that aligns with your energy and capacity, and reach out to peers or facilitators if you feel overwhelmed.

Celebrate Impact

Recognize your involvement’s impact and influence, and help others understand the value of patient partnership in research.

> My years at KRECENT as a patient partner with PCAN have been memorable. As I get ready to step down in May, I reflect on the past years. KRECENT and PCAN have come so far and changed so much with our direct interaction between patient partners, nephrologists, and researchers. Our patient partners are front and centre and very engaged and appreciated. We feel very much a part of the research process from inception to delivery.
>
> Anne MacPhee patient partner, PCAN

Life is a complex journey of highs and lows, but maintaining personal interests and traditions can keep us grounded during the doldrums.

Navigating tough times
through personal interests and traditions

Contributor: Andrea Rudy

Life is a complex journey filled with highs and lows.While the peaks often provide joy and inspiration, it's the valleys—those challenging moments—that can test our resilience and wellbeing.

Living with kidney disease comes with its own unique challenges. From managing a strict diet to attending regular medical appointments, the journey can feel overwhelming—especially during periods of stress, illness, or life transitions. During difficult times, maintaining personal interests and traditions can provide comfort and help us regain our sense of self. These activities and rituals act as anchors by offering stability, connection, and emotional sustenance.

Source of Stability and Structure

When life becomes chaotic, one of the most important things people crave is a sense of stability. Personal interests, whether they are hobbies, sports, music, or art, provide a structure that can serve as a daily or weekly touchstone. Engaging in a familiar routine like reading a book, playing an instrument, or gardening gives a sense of control in a world that may feel unpredictable.

Research shows that hobbies can have a calming effect, similar to meditation. For example, activities like painting or knitting require focus, which can take the mind away from stressors.

This immersion in a task not only fosters a sense of accomplishment but also allows the individual to momentarily escape from the burden of tough circumstances. This balance between focus and relaxation helps promote mental clarity, giving people the strength to move forward.

Emotional Expression and Release

Difficult times often come with a swirl of complex emotions—anger, sadness, frustration, or grief. For many, personal interests offer an avenue for emotional release. Creative outlets like journaling, drawing, or song writing allow people to express what they may not be able to put into words through conventional conversation. This form of expression provides a safe space to process emotions in a way that feels productive rather than overwhelming.

Adversity often pushes people to reconsider their priorities, revaluate what brings them joy, or discover new passions.

Similarly, physical activities like hiking, yoga, or dancing serve as an emotional outlet, channeling stress or anxiety into movement. The link between physical exercise and mental wellbeing is well-documented. Regular activity can lead to the release of endorphins—natural mood elevators—helping to alleviate stress and promote a sense of calm and optimism. For those with limited mobility, daily chair exercises can also help.

The Kidney Wellness Hub offers weekly online art classes, as well as on-demand dancing, chair, and yoga classes. See page 26 for information on art for wellness.

Comfort of Traditions

Traditions—whether personal, familial, or cultural—are powerful practices that provide a sense of belonging. In tough times, traditions remind individuals of their roots, history, and identity. They offer continuity, a reminder that, despite current struggles, life has a rhythm and flow that extends beyond the present. Holidays, family gatherings, and rituals create moments to pause and reflect on what matters most. These traditions often reinforce values like community, love, and perseverance. For example, lighting candles during a holiday or preparing a favourite meal can evoke a sense of comfort, grounding an individual in the familiar while providing hope for the future.

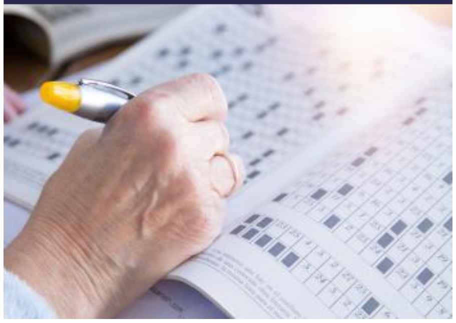
Personal traditions can be established at any time in our lives. Whether it's hosting a summer barbeque, having an annual calendar with family photos printed each year, attending a yearly festival or treating yourself to a popcorn and movie night once a month, consider starting a new tradition.

Community and Connection

Personal interests and traditions also have a unique ability to connect people with others. Joining a club, participating in a community event, or attending a traditional family gathering can foster a sense of shared experience. In tough times, being part of a community—even if it's small—can make a world of difference. Feeling supported and understood by others can help ease the emotional burden of hardship. For those living with kidney disease, social connections with those who have the same lived experience is incredibly beneficial. Peer support and engagement groups are available through the Kidney Foundation.

Shared traditions, like family dinners or cultural celebrations, are often where people find solace in each other's presence. The sense of unity created by these moments can offer strength and reduce feelings of isolation. Even when facing adversity, people find that coming together through common traditions helps them remain connected to their support systems.

When the weather is bad, indoor activities such as knitting, journaling, crafting, brain teasers like crosswords, or puzzles can help with focus and goal setting.



Have a favourite game or pastime? Consider making it a weekly activity with famliy or friends, or join a group. Enjoying the company of others provides a needed support system.

Rediscovery and Reinvention

Personal interests and traditions also provide opportunities for growth during tough times. Adversity often pushes people to reconsider their priorities, reevaluate what brings them joy, or discover new passions. Someone going through a difficult period might find comfort in taking up a hobby they had long abandoned or even discovering a new one that aligns with their current emotional state.

Additionally, traditions and rituals can be adapted and reinvented to better reflect evolving needs and experiences. For instance, someone coping with the loss of a loved one may introduce new ways to honour their memory, transforming grief into an act of love and remembrance.

In the face of tough times, personal interests and traditions act as more than just distractions; they are lifelines. They provide emotional stability, encourage self-expression, and foster connections with others. Most importantly, they remind us of the larger tapestry of our lives—our identity, our community, and our ability to persevere. Whether through the comfort of a beloved hobby or the continuity of a time-honored tradition, these practices help individuals navigate life's challenges with strength and resilience, offering hope when it's needed most.

Certified coach, Francine Gosselin, MSW, RSW, emphasizes the importance of incorporating habits that promote our wellbeing into our daily lives.

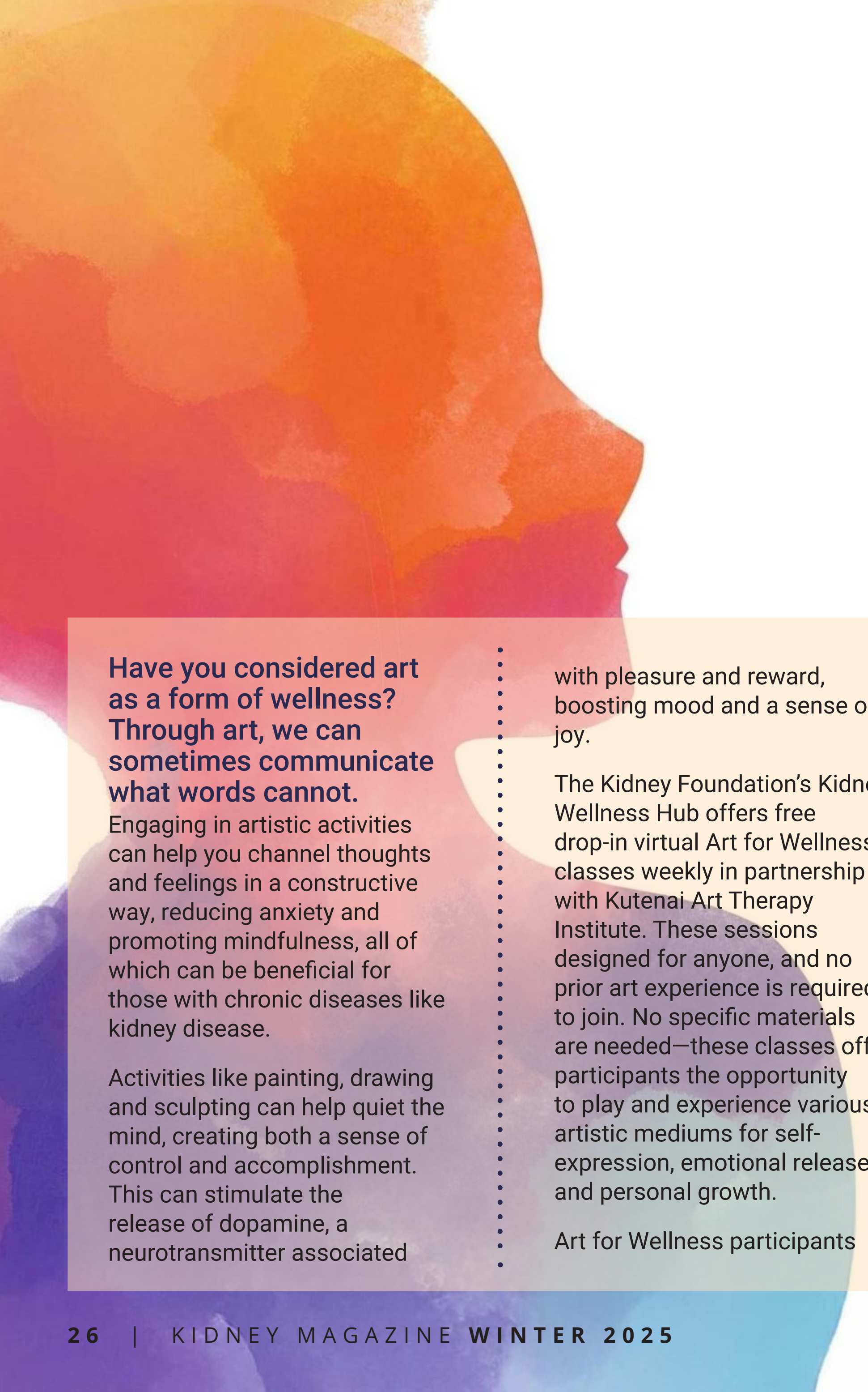
Living with chronic illness impacts one's life significantly, but it doesn't have to define them. You are so much more than your diagnosis, your care plan, or the sum of your symptoms. And yet, you are not the same person you were before getting your diagnosis. Who are you now? Ask yourself:

- Who was I before becoming unwell? How did I spend my time? What were my priorities? What was I proud of?
- What is happening for me now? What has changed?
- What makes me unique? What defines me? What parts of me are still there? What has evolved?
- What is most important to me right now? What are my priorities at this time? What do I want more of in my life? Why is this important to me?

When we are clear about what our priorities are, we can focus our energy in that direction. This is critical when our energy reserves are limited due to illness. The Kidney Wellness Hub offers free kidney wellness coaching to support health and wellness goals. Visit kidneywellnesshub.ca.

ART

Contributors: Alexandra Ireton and Jocelyn van Wynsberghe, Kutenai Art Therapy Institute



promoting emotional, mental, and psychological wellbeing

Have you considered art as a form of wellness? Through art, we can sometimes communicate what words cannot.

Engaging in artistic activities can help you channel thoughts and feelings in a constructive way, reducing anxiety and promoting mindfulness, all of which can be beneficial for those with chronic diseases like kidney disease.

Activities like painting, drawing and sculpting can help quiet the mind, creating both a sense of control and accomplishment. This can stimulate the release of dopamine, a neurotransmitter associated with pleasure and reward, boosting mood and a sense of joy.

The Kidney Foundation's Kidney Wellness Hub offers free drop-in virtual Art for Wellness classes weekly in partnership with Kutenai Art Therapy Institute. These sessions designed for anyone, and no prior art experience is required to join. No specific materials are needed—these classes offer participants the opportunity to play and experience various artistic mediums for self-expression, emotional release, and personal growth.

Art for Wellness participants shared they appreciate having a space to pause, create freely, and reconnect with themselves. They also value the sense of community created during the session and feel inspired by seeing others' creations and learning about their stories and processes.

One participant, Vivian Short commented, "Art for Wellness provides me with an individual healing space to create and, at the same time, an even greater sense of an inclusive community. Each week I look forward to this time that I have set aside for myself. Thank you to Kidney Wellness Hub and the gifted instructors."

Supporting Wellness

Process Over Product

Encourages participants to value the creative process rather than the finished product, allowing for open exploration and experimentation.

Nonverbal Expression

Provides a space for expressing feelings and thoughts through symbol, metaphor, image, writing, etc. leading to new insights and inspiration.

Nurtures Connection

Facilitates connection to creativity, senses, and materials, as well as building relationships and enhancing community in a shared space.

Personal Choice

Offers participants freedom to decide on their art direction, materials, and level of sharing about their process or art, accommodating individual preferences and needs.

Inclusive

Accessible to everyone, regardless of artistic skills or background, with spaces tailored for diverse populations and ages.

being **FORWARNED** is being **FORARMED**

Contributor: Susan Thompson (courtesy Ontario Branch)

Winter risk awareness is essential for preventing injury or health decline, especially for individuals living with a chronic disease who can face increased susceptibility to fractures and other complications from a fall. Anemia, fatigue, loss of muscle mass, and some symptoms brought on by medications, including dizziness, electrolyte imbalance, and weakness, can increase such risks. Bad weather can impact dialysis appointments and the ability to pick up prescriptions. In addition, it can dry out skin, which increases itchiness—a frustrating symptom of some kidney conditions. Use these tips to avoid these risks and ensure a healthier winter season.

Avoid Falls

Winter footwear should be well fitting and have a nonslip base. While most public places take care to ensure walkways and entrances are well salted or sanded, it is important to be prepared for slippery conditions, utilize handrails, and ask for assistance if you are presented with an unsafe situation. Ensure you use any ambulatory aides safely and that they are in good repair. Staying fit is helpful for maintaining balance and strengthening muscles that support bones. **The Kidney Wellness Hub has a number of on-demand classes to help improve core fitness and reduce these risks.**

Maintain Skin Care

Kidney disease can cause itchiness, dry skin, and rashes. Reasons for this can include elevations in phosphate levels, allergies, and changes in fluid intake. To help with winter skin conditions, take phosphate binders as directed. If having a bath, use lukewarm instead of hot water, which can leave your skin even drier, increasing itchiness. Fragrance-free soap and detergent may also cut down on irritants, and cold compresses can offer some relief. Ensure you moisturize your skin daily. This helps with decreasing the need to scratch your skin as well as making the skin more resilient to other breaks or tears. Some lotions can irritate skin, so ask your healthcare provider for assistance if you are unsure which to use.

Also, remember to keep fingernails short. Not only does it reduce the risk of scratching, but long nails can harbour dirt and bacteria. Short nails make it easier to keep your hands clean, reducing the risk of transferring germs to your skin, which can lead to breakouts or infections.

Five Ways Kidney Patients Can Prepare for Winter

3

Manage Medication

While it is always important for renal patients to stay on top of their medication, the potential for harsh weather makes this even more critical. Refill any medication you are running low on, and speak with your nurse or physician if you require a prescription renewal to ensure you always have enough medication to last a few days should you not have access to a pharmacy. You may also want to keep other supplies on hand, such as needles, syringes, or glucose stripes. Maintain a current list of your medications with you in case of emergencies.

4

Annual Flu Shot

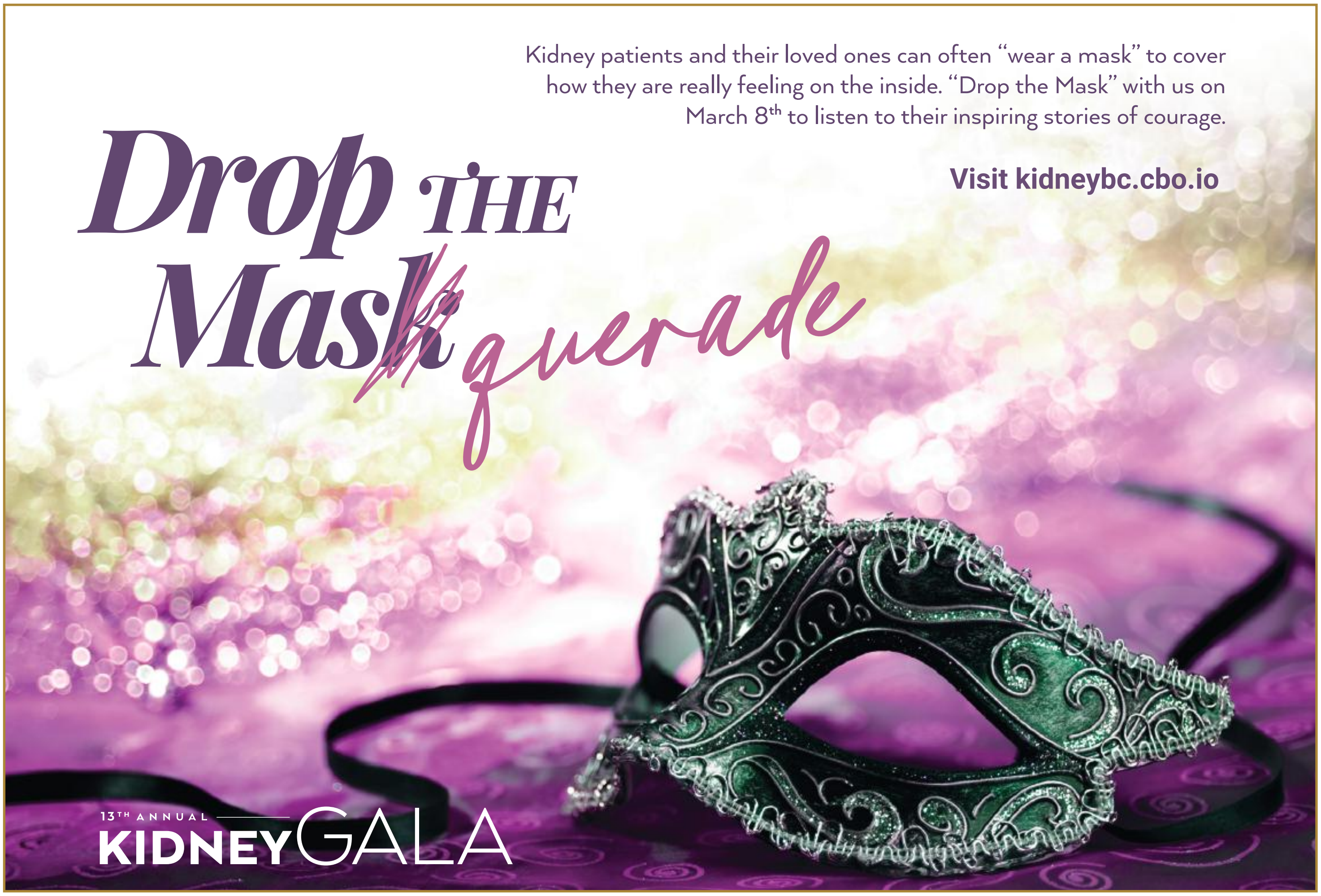
People with diabetes and kidney disease are at elevated risk for serious complications from respiratory illnesses. Getting the flu shot reduces your chances of being infected with the flu and other respiratory viruses, including COVID-19, at the same time. This helps prevent serious illness. It protects people close to you because, when vaccinated, you are less likely to spread the virus to others. According to the Government of Canada, staying up to date with all vaccinations, including COVID-19, will help to keep you protected during flu season.

5

Prep for Bad Weather

We all know that winter weather can be unpredictable. This presents a challenge when trying to keep regular dialysis appointments. Establish your back-up plan early in the season. You might need someone who can help you get to appointments. Communicate with your dialysis team, who may be able to schedule an alternative appointment. Stay aware of current weather conditions through local radio or television stations, and limit outings to those that are absolutely necessary when road conditions are bad.

If stuck at home for a few days, ensure you have extra batteries and a flashlight, and at least a three-day supply of food. Consider speaking with your dietitian about a meal plan in case of an emergency.



EXPLORE THE KIDNEY WELLNESS HUB

The Kidney Foundation's Kidney Wellness Hub is a free interactive online platform with kidney customized wellness and lifestyle tools to help you maintain your kidney health.

kidneywellnesshub.ca

VISIT TODAY

kidney wellness hub

Subscriptions

Kidney Magazine is produced by The Kidney Foundation of Canada, British Columbia & Yukon Branch. If you would like to be on the mailing list for future issues, please email your name and address to andrea.rudy@kidney.ca.

Donate to Kidney Magazine

If you enjoy our new bi-annual magazine and would like to support it with a donation, visit kidney.ca.

Kidney Magazine

Burnaby, BC V5G 4K6
Canada

Contact Us

1-800-567-8112
www.kidney.ca
bcy.social@kidney.ca

Follow Us

Facebook: @BCYSocial
Instagram: @BCYSocial
X: @BCYSocial